DOCUMENT RESUME

ED 161 111 CS 502 278

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TITLE "What tc Say" and "What Not to Say" to the Sudden Infant Death Syndrcme Parent.
PUB DATE [78]
NOTE 7p.; Study prepared at the University of Nebraska

EDRS PRICE MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS *Communication (Thought Transfer); *Death; Friendship; *Grief; *Infant Mortality; Interpersonal Relationship; *Nonverbal Communication; *Response Mode
IDENTIFIERS *Sudden Infant Death Syndrome

ABSTRACT

The responses of friends and acquaintances of parents whose child has died as the result of Sudden Infant Death Syndrome can be helpful and supportive or they can be guilt-producing, painful, and destructive. Some destructive responses experienced by parents in those circumstances include questioning such as, "Did you...?" which implies that somehow the parents were neglectful and responsible for the death; silence, which may be eloquently accusing or isolating if it is the silence of avoidance; suggestions that the baby be forgotten, which encourage the parents to deny the existence of a baby; "Well, you're young," which assumes that another baby can simply replace the dead one; and "at least" statements "at least the baby didn't suffer," "at least you have other children" which deny the validity of the parents' feelings. The most helpful responses, whether verbal or nonverbal, are those responses that allow the parents to cry, express anger, talk about guilt, and vent hostility. (TJ)

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"WHAT TO SAY" AND "WHAT NOT TO SAY" TO THE SUDDEN INFANT DEATH SYNDROME PARENT"

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Communicating with the friends and relatives of a loved one who has died is a difficult task. When the death involves an infant or a child, the task seems even more difficult. Sudden Infant Death Syndrome takes the lives of approximately 10,000 infants each year. The sudden, totally unexpected, totally unpredicted nature of this syndrome causes intense shock and disbelief on the part of the parents. And caring friends and relatives have the most difficult tasks of counseling, helping, and supporting the parents during this crisis.

As with any death, the problem of "what to say" to the grieving is ever present. In the instance of death from terminal illness, old age, and more anticipated deaths, there is a time for preparation. Informed family and friends have the time to cope with their own shock and grief. Sudden infant death allows no preparation time for the sudden infant death parent, or for friends and relatives, to resolve their immediate denial, anger, and depression. At this time, parents suffer from an acute emotional vulnerability. During the initial period of shock, when the baby is discovered, and during the hours, days, and weeks which follow, the statements made to these parents are of crucial importance. The communication statements made to the parents can greatly facilitate the natural process of grieving, or contribute more to their pain.

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The problem of "what to say" is recognized as such a crucial one that a group of Nebraska Sudden Infant Death Parents were willing to spend a weekend reliving the painful events of that loss and examining the communicative messages they perceived then. It was the hope of these parents that the recording of their feelings concerning communication surrounding the death of their baby would help others better understand "what to say." There emerged from these discussions agreement concerning those statements which gave comfort and those which contributed more to the agony.

"What did the baby die of?" The parents of a Sudden Infant Death child are confronted with and will be confronted with that statement for the rest of their lives. The typical response of the parent who received information concerning this poorly understood killer is, "My baby died of sudden infant death syndrome." Frequently, the reaction of well-meaning friends is <u>silence</u> with an accompaning, "Oh!" which says, "I really don't understand that at all." Another reaction may be, "But what caused it?" "Did the baby have a blanket on?" "Did you check it often?" "Did you. . ?" - "Did you..?" - Did you . . ?" That the baby died of sudden infant death is often not sufficient explanation for friends and relatives. It is, in fact, not sufficient for the parents of the dead child. In this age when medical science has discovered so much, had made such tremendous advances, the fact that this elusive killer is still undiscovered is difficult to understand. Had the baby died of some well-known disease or disorder, there would be no need to further explain, no need for further questioning. And, according to these Sudden Infant Death Parents, questioning creates doubt, anxiety, and

guilt on their part. The grieving parent finds himself in the uncomfortable position of defending the diagnosis of sudden infant death and explaining that the death was not caused by anything that he/she did or did not do.

The Nebraska Sudden Infant Death parents concluded that the public can take some active steps to help. As a friend, take time to read the literature on Sudden Infant Death. You can then explain to others, friends and relatives of the grieving parents, that the baby died of sudden infant death syndrome. Let everyone understand that current medical science recognizes nothing that can prevent the death. There is no recognized cause. No amount of supervision can prevent a baby's death. Knowledge about sudden infant death--that it's the single biggest killer of children, ages birth to one year, can do a great deal toward understanding and acceptance of death from this syndrome.

The problem of "what to say" is solved by some by not saying anything. The problem of saying nothing is that it can easily be misinterpreted. Silence can eloquently accuse, can wordlessly express the message, "I am not sure I want to talk with someone who has a dead baby." For the Sudden Infant Death Syndrome parent, this can contribute to feelings of guilt--"Perhaps I really did do something wrong. If I didn't, why don't my friends talk to me?" Another way of avoiding the dilemma of "what to say" is by totally avoiding any contact with the parents. Looking the other way in the supermarket, avoiding them after church all quickly solve the dilemma of "Well, I wouldn't know what to say to them." The Sudden Infant Death Syndrome Parent finds no comfort in being shunned and

avoided by friends. Left alone, the message to the parents is that they have committed some terrible wrong, whether or not that is the intent of the isolation, the avoidance.

Those friends and relatives who were able to sit and talk and listen gave much comfort to the grieving parents. Those who were able to sit and listen to all of the fears, anger, and emotions which accompanied this incredible loss were perceived as being very helpful. The friend who listened, talked without accusation, without evaluation, contributed much to the peace of mind of the parents. Friends who allowed the parent to express doubts, to cry, to vent all of the bottled-up emotions of hostility and anger without rejection and/or denial helped the parents put their confused world back into order. These friends were neighbors, doctors, nurses, other sudden infant death parents, relatives, but most of all, friends.

Sudden Infant Death Syndrome parents report a commonly expressed feeling by others that the grieving parent must forget the baby. Suggestions are made that the sooner the baby is put out of mind, the quicker the recovery from the grief. This perception results in such advise as: "Let's not talk about it; it's too gruesome." "You should remove all of the baby's pictures from the wall." It is obviously impossible for a parent to deny the existence of a baby, impossible to erase the memories of a living human being who played such a vital role in the family. This push to forget can also contribute to feelings of guilt.

A similar form of advice is offered by well-meaning friends who make statements such as: "Well, you're young, you can have more babies," or, "Have another baby. It will help you forget." The

implication is one that nobody really accepts--that one baby is just like any other one, that a new baby will replace the dead one. Sudden Infant Death parents report that, just after the death of their child, they are not in an emotional state to deal with the suggestion of having another baby.

Other people solve the problem of "what to say" with "at least" statements: "At least the baby wasn't ten years old." "At least the baby didn't suffer." "At least you have other children." The implication is that if the baby were older, or if he had suffered pain, or if there were no other children, grief and agony would be proportionately greater. It is hard to believe that anyone really accepts the above logic. Obviously the statements are intended to offer consolation by trying to minimize the situation or make other situations worse. Nevertheless, parents of sudden infant death babies, say that these messages add to their pain, because they do not deal with the parents' feelings about the loss.

So much of what human beings communicate to others occurs not in their verbal statements but in their nonverbal actions. The message of a stare, of avoidance, of tears, of hugs, can be as poignant and eloquent as endless hours of chatter and dialogue. The honesty and truth of a compassionate hug, the tenderness and understanding of a touching of hands can say clearly, "I am your friend; let me help if I can." Those individuals who could cry with parents were perceived as being most helpful and understanding. Apparently, parents put much more reliance on the truth of the nonverbal message than of words which express sorrow.

While there will never be a formula on effective communication

with grieving parents, there appears to be some communication which can help restore peace of mind and other communication which contributes more to the grief. Friends and relatives, those individuals closest to the grieving Sudden Infant Death Parents, can do much to help. Through their empathy and caring, along with their intellectual understanding of the disease, they can better know "what to say" and perhaps even more importantly know, "what not to say." It is at this time when parents truly need a friend who knows.